Measuring Chemicals in People – What Would You Say? A Boston Consensus Conference on Biomonitoring

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Consensus Conferences

- Danish Board of Technology → Parliament
 - Argentina, Australia, Belgium, Canada, Israel,
 Japan, New Zealand, South Korea

- Participatory Technology Assessment (pTA)
 - European Citizens' Deliberation method
 (Nine European countries)



Boston Consensus Conference

Objectives:

- Educate the general public and stakeholders about biomonitoring, and related ethical, legal, social and scientific issues.
- Gather input on the topic of biomonitoring from informed laypeople and learn from their unique perspectives.

Funding:

National Institutes of Environmental Health (NIEHS)

- Communications and Ethics
- Outreach and Translation,
 Superfund Basic Research Program

Why Biomonitoring?

- Scientific complexity
- Issues of controversy
- Pending legislation



Figure 5. At its Environmental Health Laboratory, CDC scientists use several types of highresolution mass spectrometry to analyze human tissue and fluid samples. The equipment shown here is being used to measure dioxin levels in a sample of blood serum. (Photograph courtesy of James L. Pirkle.)



Next Page: Executive Summary

Press Release

09/29/2006 GAAS:699:06 FOR IMMEDIATE RELEASE Print Version

Gov. Schwarzenegger Signs Biomonitoring, Greenhouse Gas and Other Important Environmental Legislation



► PLAY VIDEO

Gov. Schwarzenegger signed legislation today that would help track how chemicals are building up in our bodies, require electricity imported into the state be as clean as electricity produced in California and other important bills that will help keep our environment clean.

"There are literally thousands of chemicals being used in our everyday products in the United States in cleaning supplies, pesticides, cosmetics and more. It's important to know more about how those chemicals are building up in our

bodies or how they may be affecting our health," said Gov. Schwarzenegger. "Bio-monitoring will do

Steering Committee

- Lois Adams, EPA Region 1
- **George Annas**, JD, MPH, Boston University School of Public Health
- **Tom Burke**, PhD, MPH, Johns Hopkins Bloomberg School of Public Health
- **David Carpenter**, MD, University at Albany School of Public Health
- Howard Frumkin, MD, DrPH, National Center for Environmental Health, Agency for Toxic Substances and Disease Registry
- Carol Henry, PhD, DABT, American Chemistry Council
- **Ted Schettler**, MD, MPH, Science and Environmental Health Network



Assembling the lay panel

| | City of Boston (approx. %) | Panel of 15 (actual number) |
|-------------------------|----------------------------|-----------------------------|
| | | |
| Gender | | |
| Male | 50 | 7 |
| Female | 50 | 8 |
| Household Income | | |
| < 15,000 | 20 | 3 |
| 15 - 45,000 | 30 | 5 |
| 46 - 74,000 | 20 | 3 |
| > 75,000 | 30 | 4 |
| Ethnicity | | |
| White | 55 | 8 |
| Black | 25 | 4 |
| Asian | 8 | 1 |
| Hispanic | 14 | 2 |
| Age | | |
| 18 - 34 | 47 | 7 |
| 35 - 54 | 36 | 5 |
| 55 – 74 | 17 | 3 |



Chemicals in People – What would *you* say about it?

Should people be tested for chemicals in their bodies?

What if we can't say what results mean for health?

How much should people know?

Participate in a forum that gives Boston residents a voice on these questions. Come to 3 weekend meetings to learn about and discuss them.

You will be paid for your time. No experience needed.

For more information: info@biomonitoring06.org or 617-414-1075

Sponsored by the Boston University School of Public Health

www.biomonitoring06.org

> 100 responses

85 Questionnaires returned

~ 20 Interviews

Final 15: Teacher, great great grand-mother, truck driver, detention center staff, singer, actor ...



First weekend

- Working definition of "consensus"
- Building trust





Expert Presentations

- Intro to toxicology, epidemiology, and public health
- Intro to biomonitoring

Second weekend





Expert Presentations

- Larry Needham, CDC: NHANES biomonitoring surveillance program
- Amy Kyle, UC Berkeley: CA legislation



Lay Panel Questions

- Are there examples of corporations that have been held accountable or that have changed their behavior based on the results of biomonitoring?
- How could someone who participated in a biomonitoring surveillance program experience discrimination based on test results?
- How might biomonitoring results get translated into action and policy?
- What did California do around biomonitoring education and awareness?
- What are some perspectives on who should sit on the oversight boards of biomonitoring surveillance programs?

Third (final) weekend



Saturday- Expert presentations

Sunday- Deliberation and writing

Monday- Presentation of consensus statement

Expert Panel (morning)

- Rachel Morello-Frosch, PhD, MPH, Brown University School of Medicine Department of Community Health, and the Center for Environmental Studies
- **Julia Brody**, PhD, Executive Director, Silent Spring Institute Ethics, confidentiality and disclosure; and responsible surveillance programs
- Patricia Roche, JD, Boston University School of Public Health, Department of Health, Law, Ethics and Human Rights
 - Ethics, confidentiality and disclosure

Expert Panel (afternoon)

Roy Petre, Senior Policy Analyst, Center for Environmental Health, Massachusetts Department of Public Health Ethics, confidentiality and disclosure; responsible surveillance programs; education and communication on biomonitoring; and public policy, legislation, and regulations

Carol Henry, PhD, DABT, Vice President, Industry Performance Programs, American Chemistry Council Responsible surveillance programs; and corporate/government responsibility and accountability

Ted Schettler, MD, MPH, Science Director, Science and Environmental Health Network

Responsible surveillance programs; and corporate/government responsibility and accountability



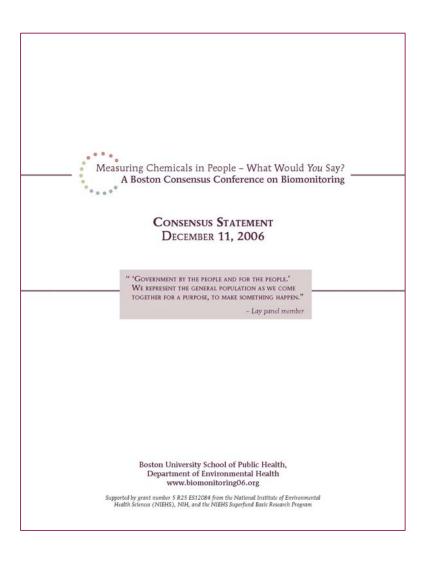




Consensus Conference: Presentation of findings



Consensus Statement



- Establishing responsible surveillance programs
- Using biomonitoring data to influence corporate and government behavior
- Educating the general public about biomonitoring
- Addressing the issues of ethics, confidentiality and disclosure
- Thoughts on public policy



Establishing Responsible Surveillance Programs

 State-based programs useful in addition to federal program

 Oversight boards should be composed of different stakeholder groups, including affected communities

 Concern that communities or individuals could be stigmatized by results



Using Biomonitoring Data to Influence Corporate and Government Behavior

 Biomonitoring data can be used to stimulate green chemistry and green companies

 Treat increasing trends in chemical exposure in a precautionary manner that seeks to reduce or eliminate exposure



Educating the General Public About Biomonitoring

- Key to achieving broad participation in biomonitoring programs
- Participation can be a point of entry into the health care system
- Information conveyed should include what is known and not known about cause and effect of exposure



Addressing Issues of Ethics, Confidentiality, and Disclosure

- Participants should be able to decide whether or not to receive personal results, "Right to know"
- With reporting, important to include action steps for reducing exposure where available
- Biomonitoring data should be statutorily exempted (like genetic testing) from being transmitted or shared with employers, insurers or others as part of the medical history



Conclusions

Value of diverse experiences

Lay people can
understand complex
information and
make useful
recommendations

A successful model for "mutual education"



"I think this panel has shown, to some degree of surprise to the scientific community, that the public can really understand the issues. This panel has moved biomonitoring forward."

> Tom Burke, Johns Hopkins Bloomberg School of Public Health, Steering Committee member and NAS panel chair

"I'm very pleased with your comments on innovation in green chemistry because innovation for the industry is really the driving force for being successful...We will take your report and really try and incorporate and integrate it into future actions."

> Carol Henry, American Chemistry Council, Steering Committee members

"This is a good way to include the voices of 'average folks' and their uniquely relevant experiences in the policymaking and public education process."

Panel member



Further Applications of "Consensus Conference" Model

21st Century Nanotechnology Research and Development Act (Dec. 3, 2003):

Requires... "public discussions, through mechanisms such as citizens' panels, consensus conferences and educational events."

National Science Foundation: Human enhancement technologies

Arizona, California, Colorado, New Hampshire, North Carolina, Wisconsin



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- Expert panel members
- Ned Crosby, Patrick Hamlett, Dick Sclove

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